

Cancer patients' views on government plans to introduce value-based pricing for medicines

A report for
Cancer Research UK

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1. Summary

In 2014 the Pharmaceutical Price Regulation Scheme, the current mechanism by which the NHS sets the price for all new drugs, will be replaced by a “value-based pricing” scheme. This will impact on the way in which treatments are assessed for use on the NHS. In December 2010 the Government issued a consultation document on how the new system should work. This prompted Cancer Research UK to issue a survey to patients, based loosely around questions asked in the consultation. This survey aimed both to gauge levels of interest amongst cancer patients in changes to pricing mechanisms in the UK, and to understand more about the views of cancer patients on the issues raised.

The survey explored the perceptions of a group of cancer patients – and some of their immediate family – of how they gained access to treatment for their cancer and how this could be improved. It also aims to explore those factors which patients consider to be most important in deciding what treatments should be made available on the NHS.

There were three main findings from this survey:

1. Overwhelmingly, **cancer patients believe that the efficacy of the drug being evaluated is either the only or clearly the main factor that should be considered when deciding whether to make a drug available on the NHS.** 67% of respondents felt that cost was not an important factor in deciding which treatment to offer.
2. Respondents stated that the most important factor in deciding whether a drug was effective or not was whether it would save lives. However, respondents also placed a strong emphasis on quality of life, with the **majority agreeing that a drug that would improve quality of life was more important than a drug that would extend life.**
3. Patients were able to comment generally on the care they had received and what could be done to improve it. Excepting improving efficacy of the treatment itself, by far the most common comment was that for many patients, **being able to continue their life as normally as possible was the most important thing that could be improved about their treatment.** When asked to rank factors that were important to them in how their treatment was delivered, the majority ranked being able to be treated at home as the most important aspect of delivery.

The number and quality of responses received demonstrate that a significant number of cancer patients have an opinion on what is important to them about their treatment. The design of a new system to decide which treatments are made available on the NHS should involve consultation with cancer patients themselves. In this way the Government can ensure that the NHS is providing the kind of service that patients want to see.

Encouragingly, a large majority of patients were satisfied that they received the treatment their doctor recommended. However, a significant minority felt that this was not the case. The Government needs to work hard to ensure that the standard of treatment available on the NHS meets the expectations of doctors and patients alike. Whatever the specifics of a new value-based pricing system, it needs to be implemented with this as its clear goal: to make the highest standard of treatment as available as possible.

2. Background

The Conservative Party manifesto published prior to the 2010 General Election contained a commitment to enable more people to “access the drugs and treatments that would prolong or improve their lives by reforming the way drug companies are paid for NHS medicines”. This commitment was carried forward into “The Coalition: Our Programme for Government” in which the Government further elaborated on this by pledging to “reform NICE and [move] to a new system of value-based pricing”. The current pricing regime, the Pharmaceutical Price Regulation Scheme (PPRS) expires at the end of 2013, at which point the government intend to move to a new value-based pricing system.

In December 2010, the Department of Health launched a consultation to canvass opinions from a variety of stakeholders on their proposals for such a scheme. This posed questions on how best the value of drugs can be reflected in the pricing system, and how a system can be developed that delivers the best health outcomes for the UK.

Currently NICE makes an assessment of a new drug or treatment through the “technology appraisal process”. They do this by considering the economic and clinical evidence and making a recommendation based on whether they consider a drug delivers value for money to the NHS. Since 2009, there has been a certain amount of flexibility built into this system through patient access schemes, which offer discounts or rebates to reduce the cost of drugs to the NHS, and NICE’s “end of life” criteria, which take a more lenient approach to drugs targeted to small groups of patients at the end of their lives. These measures have meant that several cancer drugs have been made available to patients that would not otherwise have been. However, there are still some cancer drugs which doctors consider important, and would like to make available to their patients, but which have failed to pass NICE’s cost effectiveness test. The level of demand for these treatments can now be measured through applications to the Government’s Cancer Drugs Fund, which has been running since October 2010.

The Department’s value-based pricing consultation states that the Government wants a new system with a “closer link” between the value a drug offers and the amount of money the NHS pays for it. It has a number of key objectives:

- Improve outcomes for patients through better access to effective medicines
- Stimulate innovation and the development of high value treatments
- Improve the process for assessing new medicines, ensuring transparent, predictable and timely decision-making
- Include a wide assessment, alongside clinical effectiveness, of the range of factors through which medicines deliver benefits for patients and society
- Ensure value for money and best use of NHS resources

The proposed system would include greater flexibility to set cost-effectiveness thresholds based on certain parameters. The Government proposes that the threshold be adjusted to reflect the “burden of illness”, to be defined by the severity of the condition and the level of unmet need in treatment of the illness. Value-based pricing will also seek to reflect the “therapeutic innovation and improvement” of products; in essence, a higher threshold or maximum price will be set for drugs which demonstrate a greater improvement relative to existing therapies.

The proposals aim to increase patient access to new treatments, both by increasing the value received by the NHS for money spent on new drugs, and by rewarding pharmaceutical companies for investing in “step changes” in treatment rather than more incremental advances. They also hope to focus these advances in the areas where new treatments are most urgently required. The consultation was launched to explore whether other organisations felt the value-based pricing plans have the right goals, and whether the current proposals will meet their stated aims.

Cancer Research UK wants to ensure that the setting of thresholds for treatments is appropriate for cancer patients. We have specific concerns about how the weighting of value will be set and whether, for example, end of life treatments will be given sufficient priority under the system. These drugs can often be expensive and although the extension to life may seem small, it can be significant in terms of the difference that these additional weeks or months of life can make for some cancer patients.

The Department has stated that they will seek to involve patients in the future design of the new value-based pricing scheme. Cancer Research UK believes that this is essential if the system is to truly reflect what constitutes ‘value’ to patients. This survey aims to demonstrate both that patients are willing participants in this conversation, and that they have clear ideas about how new treatments should be made available to patients on the NHS.

We hope that this survey marks the start of a programme of engagement with different patient groups, including those representing patients with both rare and common cancers, and we look forward to working with the Government and the Department as proposals for a new system of value-based pricing are developed.

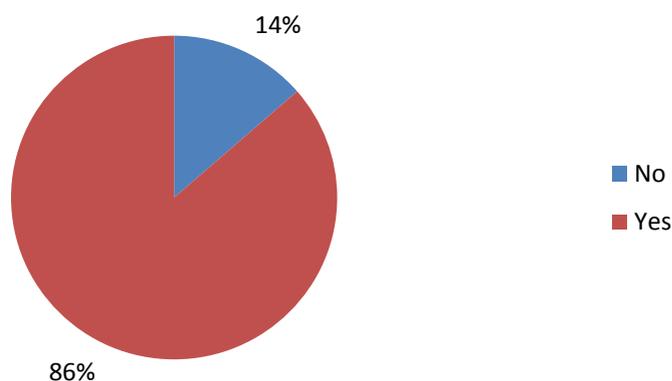
3. Findings

The survey was accessible via an internet link for three weeks in April 2011 and distributed to patients through Cancer Network User Involvement Groups across England and their equivalents in Scotland, Wales and Northern Ireland. A link to the survey was also placed on Cancer Research UK's CancerHelp and Cancer Chat websites. 147 responses were received in total, spread across a broad age range and with a good distribution across all areas of the UK. 72% of respondents were women and, as might be expected, the ages of respondents were weighted heavily towards the older end of the scale.

By far the most common cancer suffered by respondents was breast cancer with 37 incidences amongst the respondents. The most common stages of cancer for respondents were stages 2 and 3.

Overall, the overwhelming majority of respondents felt they had been able to access the cancer treatment their doctor thought they needed. However, a significant minority of 13% (20 respondents) didn't feel this, for a variety of different reasons.

Do you feel that you have been able to access the cancer treatment that your doctor thought you needed?



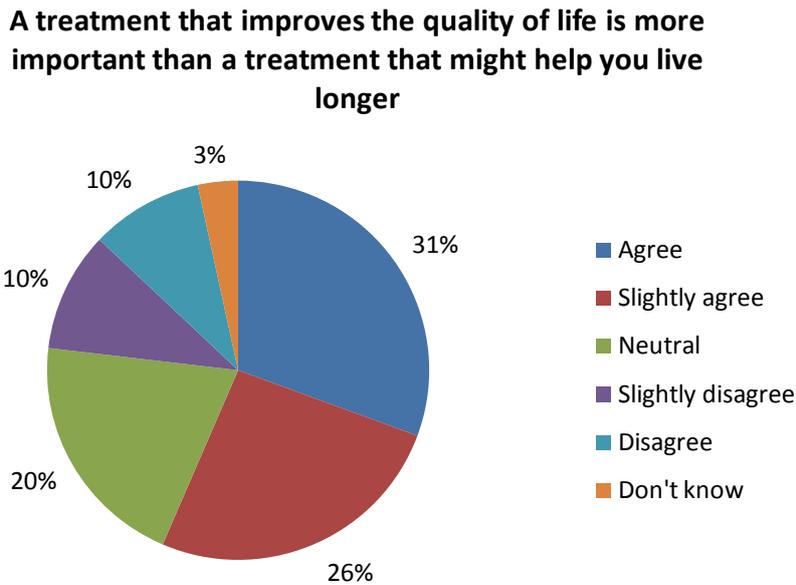
Of those who didn't feel they were able to access the treatments they needed, four people felt drugs or other treatments should or could have been offered that weren't, either because they're not available on the NHS or because they felt other, cheaper, less effective courses of treatment were offered first. There were also some negative comments from people who had been passed around consultants, who had needed to change their consultant during treatment, or who were not happy with their consultant due to perceived or real incompetence.

Communication appears to be part of the issue here, with one respondent saying "the strict answer to the above question is 'yes' because I got the best medical treatment that [my hospital] could offer. However getting information about my illness was and is difficult."

There was one comment from a patient who was only offered a drug through a controlled clinical trial, which offered a 50:50 chance of receiving the drug. A few respondents noted they were disappointed by the lack of options available – although this may reflect a lack of viable alternatives for their particular cancer.

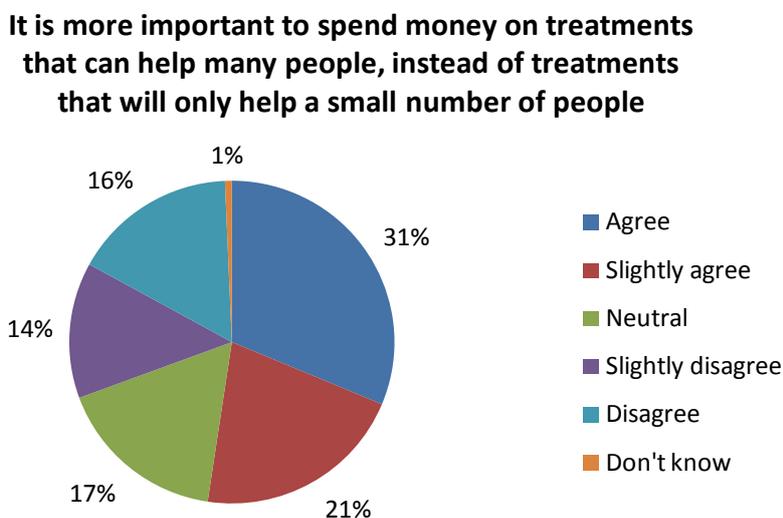
Quality of Life

31% of respondents agreed that a treatment that improves the quality of life is more important than one which might help you live longer, with a further 26% slightly agreeing with this statement. Only 10% disagreed, as well as a further 10% who slightly disagreed.



Breadth of Impact

52% of respondents agreed or slightly agreed that it is more important to spend money on treatments that will help many people rather than a small number of people. Many of those who disagreed commented that just because someone has a rarer cancer doesn't mean they should be discriminated against when it came to receiving treatment for their disease.

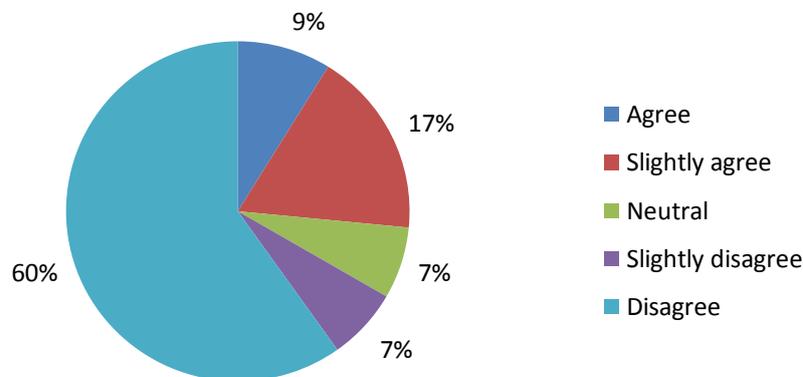


The majority of respondents (72%) agreed or slightly agreed that it is important that the treatment they are offered has been proven to work for their cancer. However there were some comments that if other treatments have failed, it should be possible for patients to receive treatments which are not proven in an attempt to successfully treat the cancer.

Cost

As might be expected, 60% of respondents disagreed that cost is an important factor for doctors to consider when deciding on treatment. Only 9% of respondents agreed, although an additional 18% 'slightly agreed' with the statement. There were many comments such as "what price is someone's life worth?" and "treatment should be decided on benefit to the patient not according to cost."

The cost to the NHS is an important factor for doctors to consider when deciding upon treatment



Comments from those who agreed or slightly agreed that cost was an important factor were mostly pragmatic about the NHS not having an infinite amount of money. There was general agreement that the efficacy of any treatment should be the first criterion on which a funding decision should be based. There were several people who cited the difficulty in balancing the "greatest good for the greatest number" with the value of an individual life as a reason why cost needed to be taken into account in a situation where resources are finite. However, these responses also recognised that it was important that decisions are not made purely on the basis of cost.

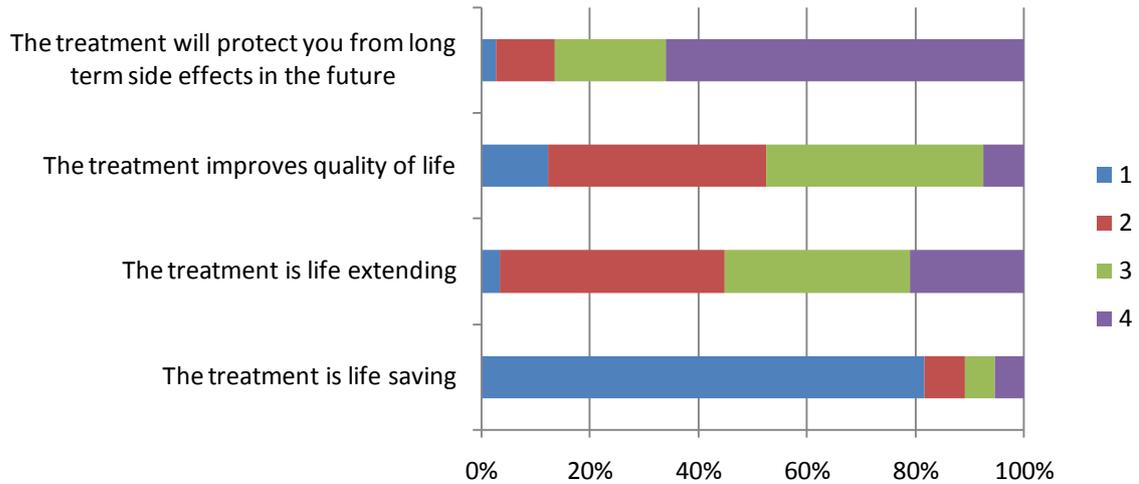
There were also several respondents who felt that cost was important, but that treatments for potentially life threatening illnesses should be prioritised very highly over other conditions, for example:

"We do need to consider cost but I can't agree with people getting breast reductions for example, when cancer treatment is refused."

The most important effect of a treatment

Overwhelmingly, people ranked the fact that a treatment was life saving as the most important factor in treatment. Life saving treatment received 82% of first choice votes, over the other statements.

The most important effect of a treatment ranked 1-4



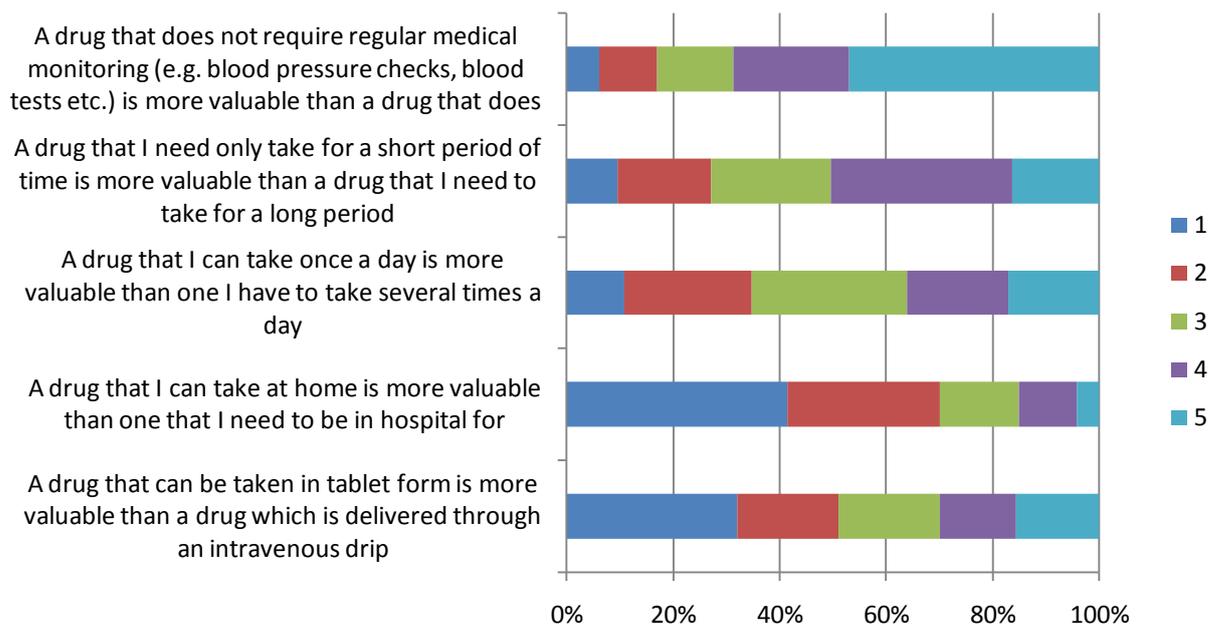
Improving quality of life was the second most popular option, closely followed by life extending treatment, with protection from side effects in the future receiving 66% of last place votes.

The closeness between the quality of life and life extending options in this question is in contrast to the heavy split in favour of quality of life earlier in the survey.

Preference for treatment methods

Having established that the fact a treatment is life saving is the single most important aspect of a treatment, respondents were then asked to rank in order of preference five statements describing what value they attributed to the method by which a treatment is given.

Preference for treatment methods ranked 1-5

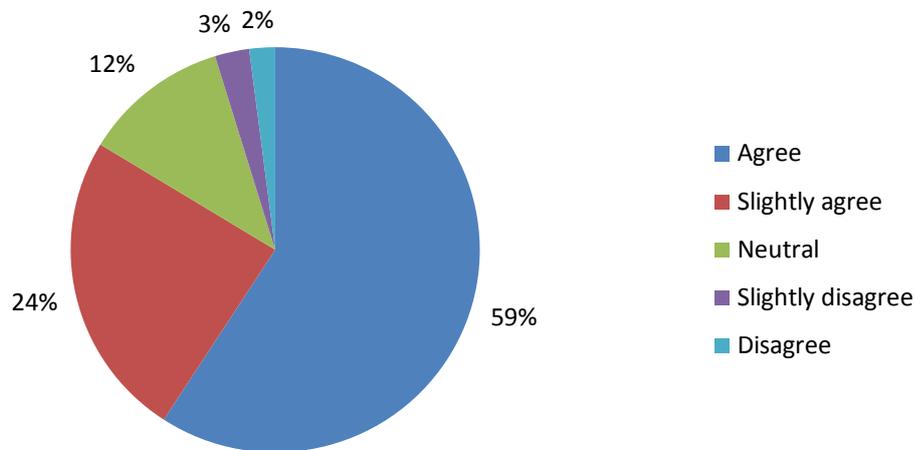


Nearly half of respondents ranked being able to take a drug at home as the single most important aspect of treatment, with 32% saying that the fact a drug was available as a tablet rather than intravenously was the most important thing about treatment to them. The amount of medical monitoring required by a certain treatment was ranked by far as the least important factor in treatment, with 47% of last place votes.

Side effects

Very few people disagreed with the statement that a drug with reduced side effects compared to other drugs is important.

A drug with reduced side effects compared to other drugs is important.



Many people stated that they would put up with any side effects if it meant treatment was successful or life saving – for example, one respondent stated “I am prepared to suffer anything for an effective treatment” and another wrote “if it meant saving my life I would suffer any side effects”. However, there were also a few side effects that people did state they wouldn’t endure for the sake of treatment. Depression was the most frequently cited of these, for reasons such as “depression affects your drive and determination to recover”. Several respondents also said they wouldn’t want to suffer hair loss and pain.

The length of time the side effects would be suffered for was important. If side effects would persist beyond their cancer being cured this would be more likely to affect a patient’s willingness to undergo treatment. One respondent wrote “permanent mild fatigue is a whole different kettle of fish to a year of extreme fatigue. A mild symptom becomes extreme if it presents long term”.

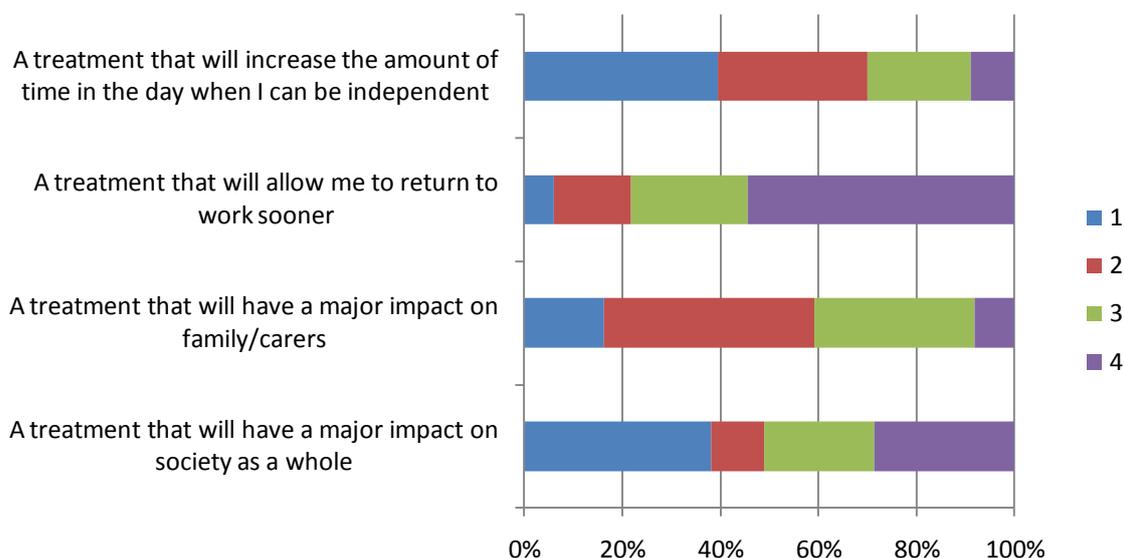
Impact of a treatment

Respondents were then asked about the value they attach to the impact of a treatment. They were again given four statements to rank in order of importance.

Treatments which increase the amount of time you can be independent was ranked as the most important statement of the four. Whether or not a treatment has a major impact on society was a polarising statement, getting almost as many first place votes as increasing independence, but also receiving the second most last place votes.

It is interesting that this appears in contrast to responses to the earlier question about treatments affecting a large number of people rather than a smaller group.

Impact of treatment ranked 1-4



The impact on family was the second or third most important statement for most respondents, but only the most important factor for 16% of people.

General comments about cancer treatment

Finally, respondents were asked a number of open questions about what was important to them about cancer treatment. The most commonly cited aspect of treatment (other than the treatment itself working) was that it will “prolong life and give good quality of life”. There were several comments similar to this.

When asked what they thought would most improve the treatment they had received, several people said that they felt communication between GPs, consultants and patients could be improved.

This echoes a similar finding in the 2010 National Cancer Patient Experience Survey¹ that one in ten people answered that only sometimes, or never: “Did the different people treating and caring for you (such as GP, hospital doctors, hospital nurses, specialist nurses, community nurses) work well together to give you the best possible care”.

While the majority of people in our survey felt they had received the care their doctor had recommended, there were still several comments in this section commenting that treatment should be “joined up between various branches e.g. oncology, surgery and GP” and that “better communication between GPs, hospital staff and patient” was important.

Several people also reported long travel times to receive their treatment, and that reducing this would be a major positive step. Similarly, many respondents commented that more could be “done at home to help fit in with the patient”.

There were also several people who said they had no problem with their treatment.

¹ National Cancer Patient Experience Survey Programme, 2010 National Survey Report, p.84

It is worth noting that throughout the free comment questions there were several comments that the “postcode lottery” should be abolished, or that it was ridiculous that “a large section of cancer patients are discriminated against” because they can’t receive a treatment in one area of the country compared to another. This demonstrates not only that variations in access to treatment persist, but also the importance that this fear of not being able to access treatment has in dictating public opinion about cancer treatment. It is important that the Government not only ensures that the new system of value-based pricing is properly implemented to ensure that all patients have equal access to treatment regardless of where they live, but also that the impact the changes to drug pricing, and the role of NICE, will have on the availability of treatments is effectively communicated to dispel these fears.

Conclusion

Although the majority of patients get the treatment they need, access to treatment remains a real concern for many of the respondents. A value-based pricing system will need to address these concerns, whether they are currently justified or not.

The respondents to this survey had clear ideas about what was important to them about their cancer treatment. The independence and quality of life of patients undergoing chemotherapy was a recurring theme throughout the comments in the survey. How to attach a value to these kinds of factors under a value-based pricing system will take careful consideration and consultation with patients.

Similarly, the value afforded by a treatment offering reduced side effects will also need to be considered. The responses to the survey clearly showed that this is an important issue for cancer patients. However, attaching a value to a treatment which may be no more, or only marginally more, effective therapeutically but offers substantial quality of life improvements is not a trivial process.

It is clear from the results of the survey that patients want to be involved in the debate about how drugs are made available and many have strong opinions on the subject. The results also show that the majority of patients do not share the Government’s preoccupation with cost effectiveness.

The Government will need to address how they approach this issue, and also take steps to fully and effectively involve cancer patients and their families in the process of shaping the value-based pricing system if they are to realise the ambition of “no decision about me without me”.

4. Recommendations

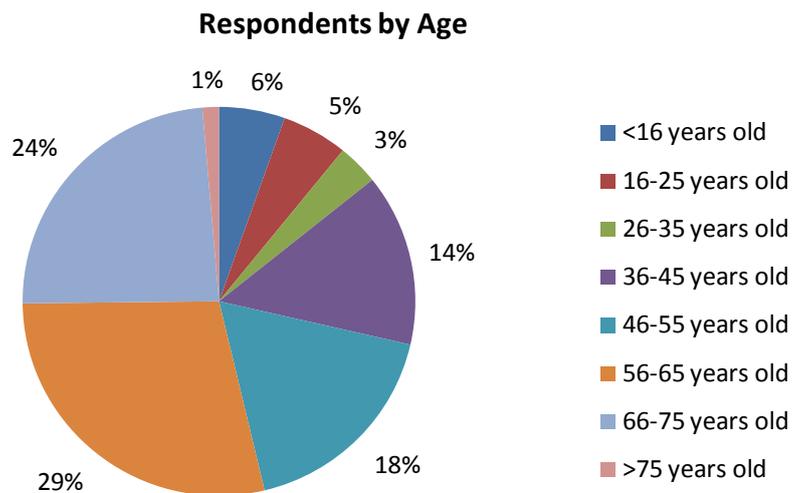
This survey has not sought to define how a value-based pricing system might be implemented, but rather to inform the process by which this should be defined.

The following recommendations, therefore, address how the Government should go about shaping the value-based pricing system, rather than the shape the finished system should actually take:

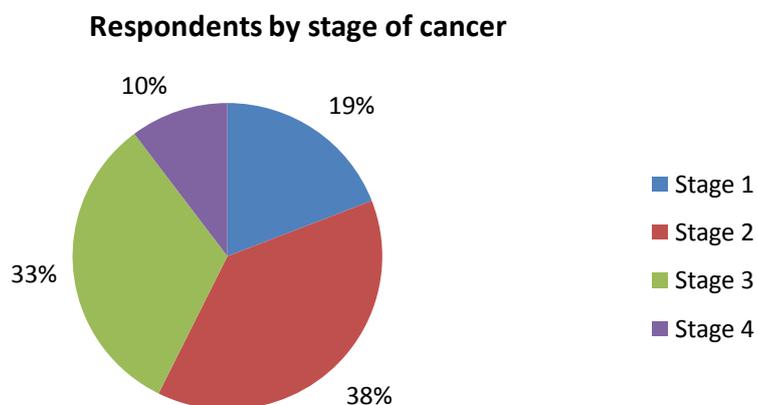
1. The development of value-based pricing should **actively involve patients** in order to effectively reflect their priorities with regards to treatment. This survey has shown that patients have strong opinions on how new treatments should be prioritised, and in order to ensure maximum value is gained for patients, these views should be fully reflected in the design of the new system.
2. The new scheme should be able to take into consideration **other factors that are important specifically to cancer patients**, such as place of administration or side effect profile. These factors are significant to patients undergoing long and arduous programmes of treatment such as chemotherapy, but which may not be adequately accounted for under the “burden of illness” criteria laid out by the Government in the recent consultation.
3. More needs to be done to overcome the **perception of a postcode lottery** which spreads fear amongst cancer patients. It is therefore important that assurances are written into the new scheme that value-based pricing will not lead to variations in local availability.
4. It is extremely important that, however the new value-based pricing system is designed, **how it will work in practice is effectively communicated to patients**. Many of the comments in this survey show how important patients’ perceptions of treatment availability can be. In particular, reassuring patients that they will have access to the treatment they require, and that they will not be denied treatment on the basis of price, will be essential.

Appendix – Methodology and Demographics

This survey was sent out to Cancer Network User Involvement Groups across England, and equivalents in Scotland, Wales and Northern Ireland, via an internet link. It was also posted on Cancer Research UK's CancerHelp and Cancer Chat websites. There were 147 responses in total: 72% female and 28% male. The age range of the respondents was broad, with the largest single group of respondents being 56-65 year-olds. This was not unexpected, as this is the age group with the highest population of cancer patients.



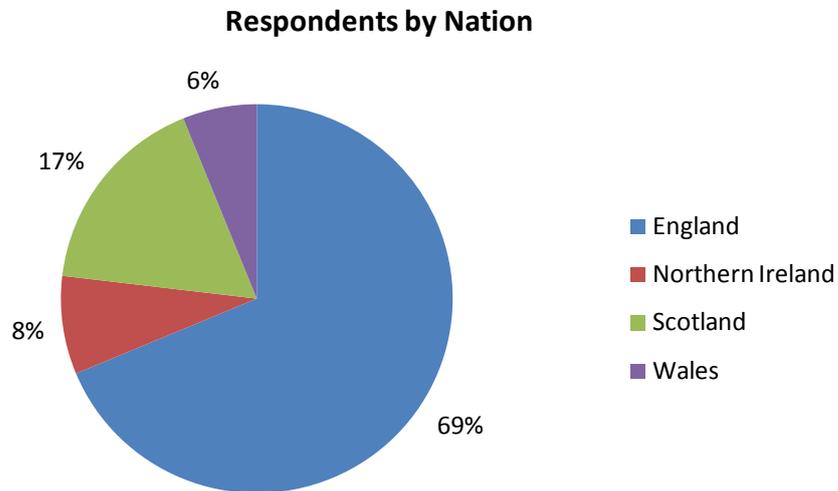
A broad range of different cancer types and stages were captured in this survey. Breast cancer was by far the most commonly reported cancer amongst respondents, as might be expected in a largely female sample, with 37 respondents. It was difficult to accurately compare other cancer types between respondents, as this was a free text field and people were often very specific about their particular cancer type, resulting in many unique entries.



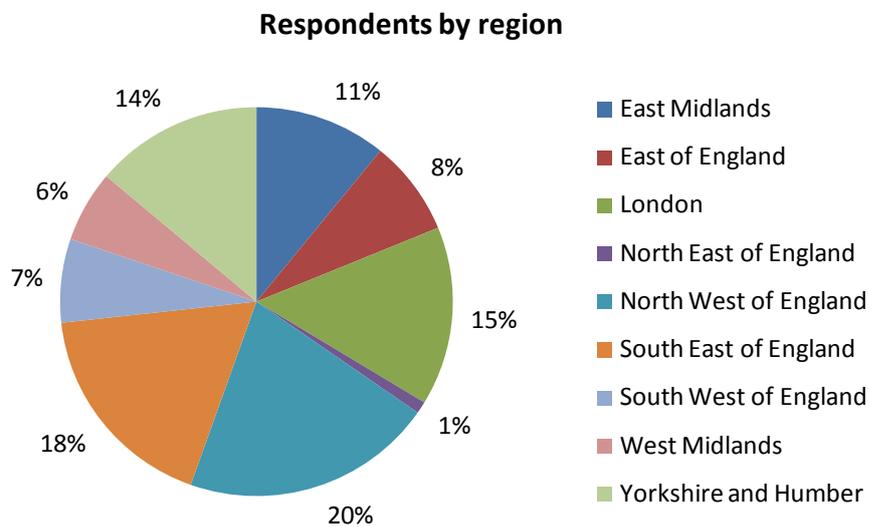
Similarly, the stage of cancer was a free text field, resulting in many different interpretations of the question. Of those who simply listed a stage from 1-4 (the most

easily comparable results), the most common was stage 2 (38%), closely followed by stage 3 (33%).

Respondents came from across the UK, with more than would be expected simply on population level coming from Scotland, Wales and Northern Ireland.



Those respondents living in England were geographically well spread throughout the nation, with the North East of England being the only region with fewer than five responses.



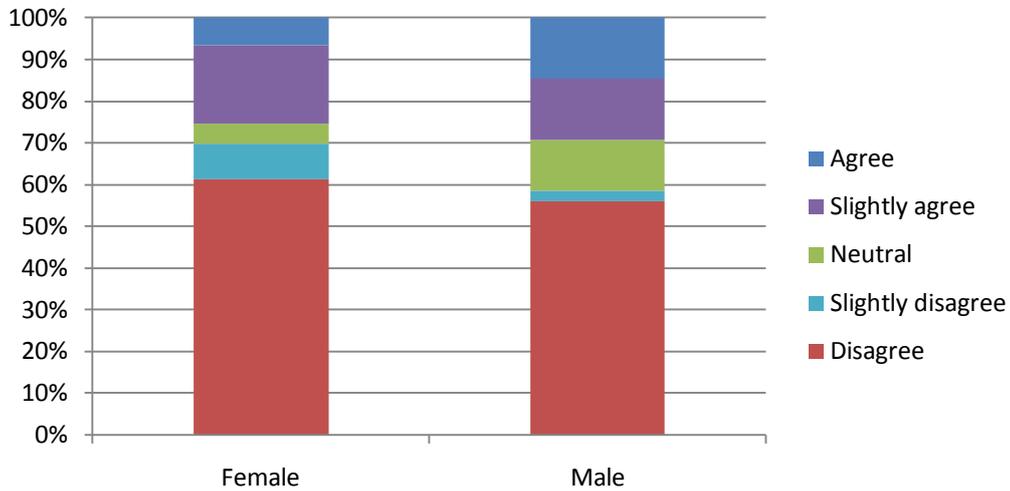
Filtering responses by demographics

We thought it might be interesting to explore differences in responses when filtered by this demographic information. As one respondent commented “I think that these responses might change depending on [the] type and stage of cancer that someone has personally experienced”.

Several of the questions were filtered according to the demographic information to look for patterns. For example, filtering the question about the importance of cost by gender shows that the male respondents were slightly more likely to agree that cost is an

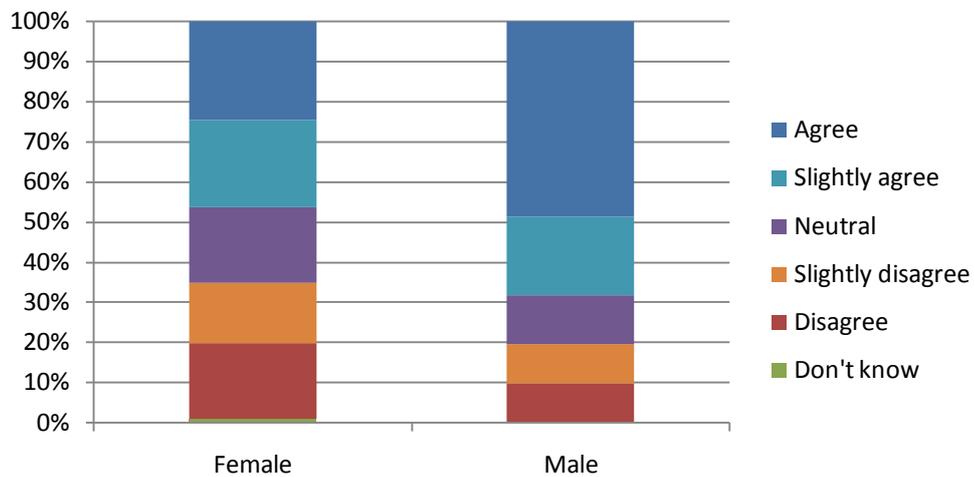
important factor in deciding which treatments should be available, and more likely to be neutral to the idea.

The cost to the NHS is an important factor for doctors to consider when deciding upon treatment



Some differences were starker:

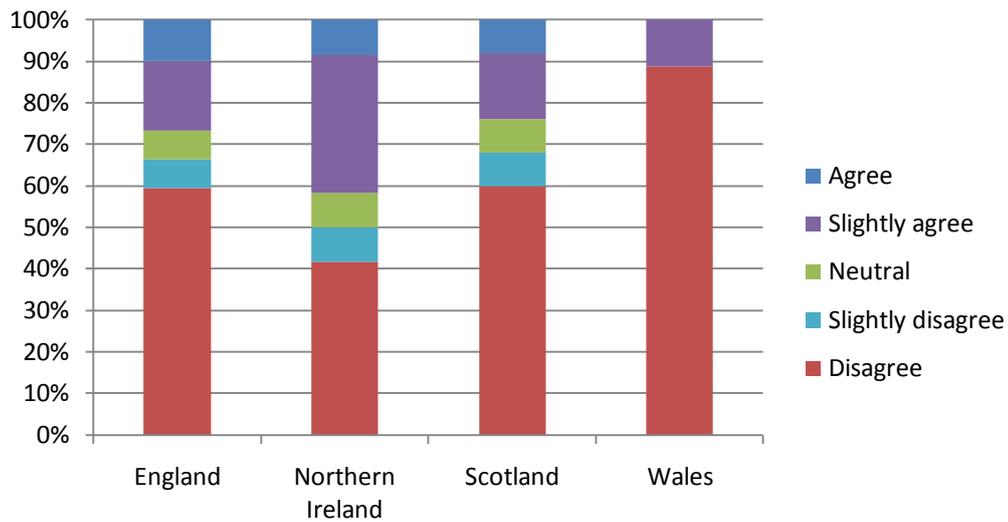
It is more important to spend money on treatments that can help many people, instead of treatments that will only help a small number of people



However, when most of the responses were looked at in this way, there was either little difference between the different segments of the population, or the sample size was too small to provide a statistically significant result.

This proved to be the case when looking at results by region. In the following graph England and Scotland have near identical percentage results, whereas there appear to be substantial differences in responses from Wales and Northern Ireland. However, as only 9 responses were received from Wales and 12 from Northern Ireland, it is difficult to draw conclusions from this.

The cost to the NHS is an important factor to consider when deciding upon treatment - by country



The same issue was encountered when looking at the data by cancer stage or cancer type. Accurately correlating responses to type of cancer was complicated by the fragmented nature of the data – for example comparing one response for “acute myeloid leukaemia” and the 37 responses from people with breast cancer.

It was also clear from many of the comments on the survey that several of the respondents were not actually cancer patients themselves but were completing the form on behalf of a loved one who had. It may be interesting in future to compare how responses from family and friends on these issues compare to the responses from patients themselves.

In future surveys, we would therefore recommend the inclusion of categories for cancer type and stage rather than free text to enable deeper analysis of the data. Respondents should also be asked whether they are a cancer patient or if they are answering on behalf of someone else.

Acknowledgements

Many thanks must go to everyone who responded to this survey. Special thanks also are also due to Emily Unwin, Sarah Broughton and Caroline Horton for their help in the design and distribution of this survey.